

Investigating available resources on loss from a multiple pregnancy to inform practice

The loss of an infant has a huge emotional impact on both the parents and the health professionals involved in their care. When the loss is from a multiple pregnancy, parents may find themselves supporting a living sibling while suffering from the loss of another. This article describes a process (scoping review) of searching for available resources relating to loss from a multiple pregnancy to aid in the development of a training package for health professionals caring for parents who have suffered a loss of this kind.

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Key points

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1. A process of searching for available resources relating to loss in a multiple pregnancy is described.
2. Regarding care received by parents, the scoping review reveals recurring themes from many different sources.
3. Guidance for health professionals caring for parents who have suffered a loss from a multiple pregnancy is scarce.
4. A need for further research and training in the area of loss from a multiple pregnancy is demonstrated.

The loss of an infant from a multiple pregnancy, at any stage of pregnancy and in the neonatal period, is a complex situation and parents can experience high stress levels that emotionally impact on both parents and the health professionals involved in their care. The parents may find themselves caring for a surviving sibling(s) while mourning the loss of another/others. They may also find that the right support is not available at the time of loss.

A recent qualitative research project conducted at Newcastle University in partnership with the Newcastle upon Tyne Hospitals NHS Foundation Trust and the charity Tiny Lives Trust,¹ studied parents who have experienced a loss from a twin pregnancy, and health professionals involved in their care. In this interview-based study, it was shown that there are a specific set of issues for parents who have lost an infant from a twin pregnancy and that small changes in practice made a substantial difference to parents' well-being during their time in hospital with a surviving baby.¹ In a follow-on study, funded by the Academic Health Science Network North East and North Cumbria in partnership with Tiny Lives Trust, the authors aim to translate the findings into a resource for health professionals. This will take the form of guidance for staff dealing with parents who experience loss from a multiple pregnancy. The project involves two phases: firstly a review of existing literature and resources (scoping exercise) and secondly, a review of the interview

transcripts from the previous study to identify specific training needs for professionals. These two components will then be combined to produce written guidance for professionals. The article presented here discusses the first phase of this work, a scoping review to identify existing resources.

Research surrounding parents' experience of pregnancy loss is continually growing, with literature available discussing the emotional impact upon parents.²⁻⁵ *Better Care, Better Lives*, the Department of Health's national strategy for children's palliative care, put forth recommendations that the emotional care of the wider family before and after the child's death be considered alongside care of the child.⁶ However, there is less research on the experience of loss from a multiple pregnancy.⁷ This is an area of neglect despite the fact that the rates of multiple pregnancies continue to rise due to increasing maternal age⁸ and the use of assisted reproductive technologies.^{9,10} The risk of adverse outcome is also known to be higher in multiple pregnancies.^{11,12}

For parents with a multiple pregnancy, the National Institute for Health and Care Excellence (NICE) recommends increased monitoring and contact with specialists.¹³ The need for psychological support for parents facing a high-risk pregnancy is also acknowledged in these guidelines. It is, therefore, of utmost importance that staff are well equipped to deal with the emotional stress parents are experiencing.

The complex set of emotional needs

following a loss from a multiple pregnancy differ from those following a loss of a singleton.^{14,15} However, many hospitals are reported to have inadequate services in place to deal with these specific emotional needs.¹⁶ The perspective of bereaved parents who have lost an infant from a multiple pregnancy is neglected in research in general, with existing research focusing on specific elements, eg end of life decisions¹⁷ and measurement of grief and depression.¹⁸

Methodology and findings

The international research literature, reports, medical guidelines, internet support links found through the Google search engine, relevant journals, and the Web of Science search for other researchers investigating in this area are detailed below, to inform health professionals of the available resources and to offer a guide to undertaking scoping reviews.

Recent reports

In 2014, the National Perinatal Epidemiology Unit (NPEU) published a report

entitled *Listening to Parents After Stillbirth or the Death of Their Baby After Birth*.¹⁹

While this study did not focus exclusively on multiples, these were included. The report highlighted clear gaps where women felt their care and facilities could have been mapped more appropriately to their needs. A number of recommendations for future practice were reported including:

- policies that address the psychosocial and practical needs of parents at the time of death and afterwards
- informed choice
- policies that recognise the needs for appropriate facilities that are separate from antenatal clinics, labour or postnatal wards.

Professional networks

A number of professional networks were searched during July 2014 to establish whether there were any existing guidelines relating to loss in multiple pregnancy. The following search terms were used:

- 'guidelines loss from a multiple pregnancy'
- 'loss from a multiple pregnancy'
- 'guidelines for professionals loss from a

multiple pregnancy'

Neither the Royal College of General Practitioners nor the Royal College of Paediatrics and Child Health, returned any relevant findings. The Royal College of Obstetrics and Gynaecology's (RCOG) report entitled *Late Intrauterine Fetal Death and Stillbirth*, has some advice relating to loss, including:²⁰

- not persuading parents towards a particular course of action
- not making assumptions
- birth of a healthy baby does not compensate for a previous loss
- resurgence of grief may be triggered.

A search of the Royal College of Midwives returned two articles entitled *Registration of Stillbirths and Certification for Pregnancy Loss Before 24 weeks' Gestation* and *Assisted Reproduction: What do Midwives Need to Know?* Neither article had any information specific to staff training and loss from a multiple pregnancy.

General search via Google

A search was conducted through Google using the term 'bereavement following a multiple pregnancy'. The first page of results was reviewed and any relevant information was followed up. The results (FIGURE 1) included:²¹⁻²⁶

- Twins UK
- Twins and Multiple Births Association (TAMBA)
- Multiple Births Canada (Naissances Multiples)
- BabyCentre
- Multiple Births Foundation
- Center for Loss in Multiple Birth (CLIMB).
- a number of websites listing relevant organisations

Many of the websites are not specific to loss, eg Twins UK, but feature a page or a link specific to loss. Similar themes were often repeated throughout the different sites, many of which supported the findings from the authors' recent research study. A list of these themes from this general web search is included in TABLE 1. It is noteworthy that many of these websites were aimed at mothers rather than health professionals and, while the general web search revealed no specific guidelines for health professionals, a number of suggestions were noted (TABLE 2).

A search of the Bliss (special care baby charity, www.bliss.org.uk/multiple-births) and Sands (stillbirth and neonatal death

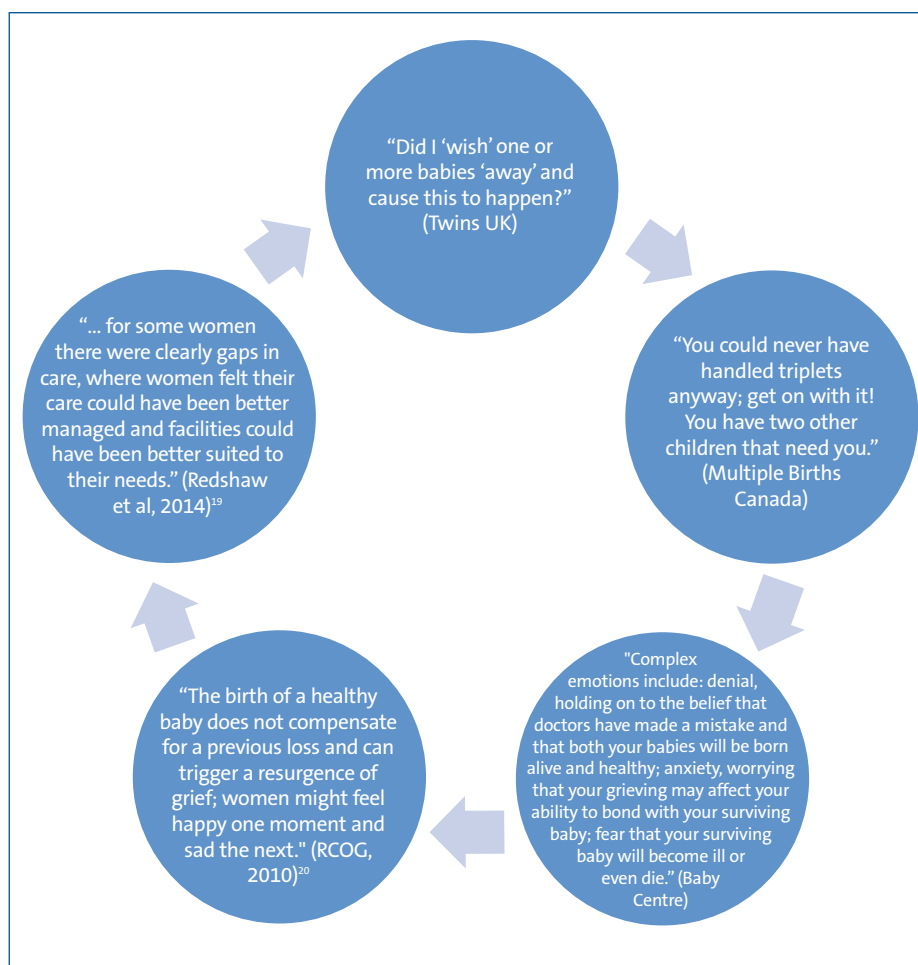


FIGURE 1 Illustrative quotes taken from websites identified in the internet searches.

charity, www.uk-sands.org) websites did not identify anything specific to loss from a multiple pregnancy.

Social media

A general search on Twitter with the term 'bereavement/loss from multiple pregnancy' yielded no results. A general search on Twitter with the term 'pregnancy loss' generated a lot of results. Many of these results were from wide-ranging organisations tweeting about pre-conception, pregnancy, birth and parenting (eg @pregnancyorg, @thebump); some were specific to pregnancy loss (eg @BLS_Campaign, @PregnancyLoss, @SIDS_Resource, @ocwalk); and some were from parents who have experienced loss (eg waiting mom @cantchoosewhen). A number of these feeds were 'followed'.

Of the feeds that were followed, past tweets were read. Neither Twins UK, TAMBA nor BabyCentre revealed anything on the loss of a multiple within the last six months (prior to 26 July 2014). Baby Loss Awareness had recent tweets and is specific to pregnancy and baby loss, but not specific to loss from a multiple pregnancy. From this Twitter feed, others were found and feeds were received, but there were no tweets relating to loss from a multiple pregnancy.

A general search on Facebook (25 July 2014) using the term 'loss from a multiple pregnancy' yielded no results. Searching 'pregnancy loss' revealed a page entitled 'miscarriage and pregnancy loss'. There was also a page entitled 'twin or multiple pregnancy loss', but this was a closed group. On 31 July, the 'miscarriage and pregnancy loss' Facebook page was searched more thoroughly; there were parents who had suffered loss from a multiple birth, but no public posts specifically targeted loss from a multiple birth solely. This page featured several references to insensitive comments, again, not exclusive to health professionals, but echoed in other sources.

NICE

The search term 'loss from a multiple pregnancy' was used to search the NICE website. The NICE guideline entitled *Multiple Pregnancy: the Management of Twin and Triplet Pregnancies in the Antenatal Period*, does not include any discussion related to professional training or guidelines related to loss from a multiple pregnancy.¹³

Loss of a unique parenting experience
Parents struggling with complex emotions; joy of the birth of the healthy infant(s) mixed with loss of another/others
A live birth does not compensate for the death of another baby
Parents ask complex questions about what has happened, eg 'Why this baby?' or 'Did I cause this to happen?'
Parents being encouraged to consider a miscarriage or stillbirth as something less than a 'real' death.
The use of the term miscarriage does not capture the extent of the bereavement or the real impact of losing a baby.
Friends and family struggling how to understand and help
Lack of sympathy from friends and family when there is a surviving baby
Parents should be vocal about their wishes. Examples include the loss of a twin and the hospital recording the birth as a singleton. Recognising all births as important no matter when the death occurred.
Inappropriate comments: 'It's not the same as losing a baby', 'You are young, you can have other children', 'At least one survived'.
Seeing their dead infant(s) and creating a memory box. Suggestions including naming the baby, dressing them, holding them
A different kind of loss
Difficulty caring for a surviving baby while grieving the loss of another/others
Parents unable to find a safe place to express grief, for example: A mother approached by another grieving mother who said: 'Why are you here? You have a baby, I have none.' A mother of two surviving triples who reported she was 'not allowed' to mourn the loss of her baby and subjected to inappropriate comments and opinions when she tried to acknowledge his birth and death, resulting in her feeling guilty about mourning him while having two other healthy babies. In the end she kept her thoughts and feelings to herself. She reportedly became very depressed.
Grief may emerge later, such as at significant milestones of the surviving twin

TABLE 1 Recurring themes on loss from a multiple pregnancy from the general web search.²¹⁻²⁷

NHS website

The search term 'loss from a multiple pregnancy' was used on the NHS website (www.nhs.uk). Although this search returned a number of results, they related to pregnancy more generally rather than pregnancy loss. However, the first result described a real life story of losing a twin told from the perspective of the parents. A list of advice for friends and family to help understand and support parents who have lost a twin is offered.

Other medical bodies/websites

Another general website search was conducted that specifically sought other professional guidelines outside of the UK. A number of guidelines were accessed, however, many did not have anything relating to loss from a multiple pregnancy. Some did have small references which have already been noted elsewhere. For example,

- Be empathetic and do not judge parents for certain behaviours
- Record all births no matter when the death occurred
- Give opportunities to parents to see and hold their babies, seeing siblings together when possible
- Avoid insensitive comments to parents of healthy twins within earshot of bereaved parents
- Remember the death of the infant(s) may be associated with a certain place

TABLE 2 While the general web search revealed no specific guidelines for health professionals on loss from a multiple pregnancy, a number of suggestions were noted.

the National French College in Obstetrics and Gynecology (CNGOF) guidelines recommended psychological counselling after the death of a twin.²⁸

Journals and Web of Science

The 2013-14 editions of *Twin Research and Human Genetics* and *Journal of Paediatrics and Child Health* were searched for relevant articles. None relating to multiple pregnancy loss and/or professional training were found. The search term 'loss from a multiple pregnancy' was also used in the Google Scholar search engine. The search was narrowed to 'since 2013' with the first three pages reviewed. Web of Science was also searched with this term; only the abstract discussing the authors' original academic research was found.

Grey literature

The Newcastle University library was used to conduct a grey literature search through the 'grey literature for medical sciences' page. The term 'loss from a multiple pregnancy' yielded no results. The search term was changed to 'pregnancy loss' that again yielded no results. The following terms were searched on the library's grey literature database:

- loss and pregnancy
- loss and baby
- death and pregnancy
- death and baby
- pregnancy loss
- pregnancy death
- stillbirth
- neonatal death
- termination of pregnancy
- infant death
- professional training
- twins.

There were no results for any of these terms.

NICU-NET

A NICU-NET (an email-based discussion forum for neonatal intensive care issues) request by one of the co-authors (NE) for resources and information, led to a recommendation to visit the Berlin Department of Neonatology website. While this website is not exclusive to multiples, much of the principles of the importance of supporting the family and encouraging parent-child bonding were present. The simultaneous feelings of joy and anxiety were recognised with support measures in place for such instances. There were numerous other sources of information available on this website, however access was limited due to the language barrier.

Conclusion

This process has shown that there is a gap in the care given to parents after a loss from a multiple pregnancy and there is also a gap in the guidance available to health professionals to aid this care. These findings support the authors' recent research study that concluded these same points.¹ Similar issues have also been echoed from numerous sources, strengthening the argument for additional research and resources in this important area.

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